



## Neural Tube Defects (NTDs)

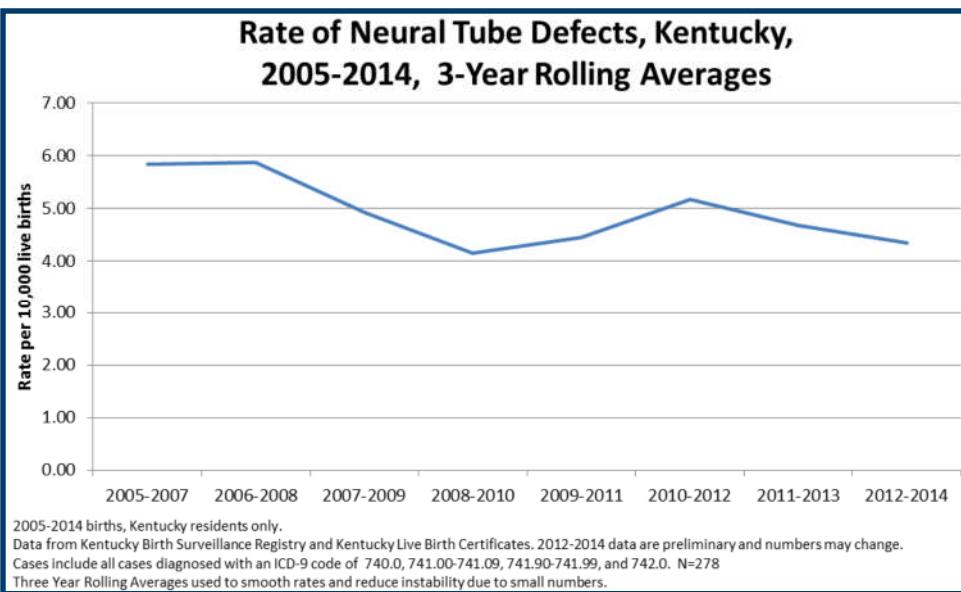
Neural tube defects (NTDs) are a group of birth defects that affect the central nervous system. The neural tube usually closes around the third or fourth week of pregnancy.<sup>1</sup> For babies with NTDs, the tube has not closed properly.<sup>2</sup> The three defects that comprise NTDs are **anencephaly**, **spina bifida**, and **encephalocele**. More information can be found about these defects on the back page.

### Causes

It is believed that most NTDs occur due to a combination of genetic factors and environmental factors (such as not having enough folic acid or vitamins in the diet).<sup>2</sup>

### How Common are NTDs?

- In Kentucky, about 28 children are born with an NTD annually, or about 4.9 cases per 10,000 live births.
- In the U.S., about 2,203-2,604 children are born with an NTD annually.<sup>3</sup> Estimates of the US prevalence of NTDs vary from 5.5 to 6.5 cases per 10,000 live births, depending on surveillance methodology.<sup>3</sup>
- The rate of NTDs is declining in Kentucky (see graph) as well as in the U.S. (not shown). Much of this decline can be attributed to the fortification of grains and grain products (including wheat flour) with folic acid.<sup>2</sup> More information about prevention of NTDs can be found on the back page.



### References

1. National Institutes of Health. Spina bifida fact sheet. National Institute of Neurological Disorders and Stroke. [http://www.ninds.nih.gov/disorders/spina\\_bifida/detail\\_spina\\_bifida.htm](http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm). Last updated February 23, 2015. Accessed November 19, 2015.
2. Centers for Disease Control and Prevention. Spina bifida facts. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/spinabifida/facts.html>. Last updated September 29, 2015. Accessed November 19, 2015.
3. Williams J, Mai C, Mulinare J, et al. Updated estimates of neural tube defects prevented by mandatory folic acid fortification — United States, 1995–2011. MMWR MMWR Morb Mortal Wkly Rep 2015;64(01):1-5.

## Types and Prevalence of NTDs

**Anencephaly** occurs when the upper part of the neural tube does not close and the baby's brain and skull fail to form completely.<sup>4</sup> The baby is born without the forebrain (front of the brain) and the cerebrum (area of the brain where thinking and coordination occur). Without a complete brain, a baby's body cannot grow and function.<sup>4</sup> Unfortunately, there is no treatment for children with anencephaly and most affected babies die shortly after birth.<sup>4</sup>

Anencephaly		
	Number of Cases Annually	Rate per 10,000 live births
Kentucky	7	1.6
U.S.*	859	2.0

Spina Bifida		
	Number of Cases Annually	Rate per 10,000 live births
Kentucky	17	3.0
U.S.*	1460	3.5

**Spina bifida**, also known as myelomeningocele, is a condition that causes the spinal nerves to bulge through an opening in the back<sup>2</sup>. The myelomeningocele usually occurs in the lowest part of the spine but can possibly occur at any level.<sup>5</sup> Lesions that are higher along the spine affect more of the nervous system and are more severe. Spina bifida is the most common permanently disabling birth defect that is compatible with living into adulthood.<sup>5</sup> Complications can include partial or full paralysis of the legs, inability to control bowel or bladder function, obesity, skin breakdown, seizures, eye disorders, and learning disabilities.<sup>5</sup>

**Encephalocele** occurs when the neural tube does not close completely and there is an opening in the upper part of the skull, the area between the forehead and nose, or the back of the skull.<sup>6</sup> It is described as a sac-like protrusion of the brain and its membranes through an opening in the skull.<sup>6</sup> Sometimes encephalocele is associated with other nervous system problems, motor coordination, developmental or intellectual delays, seizures, and vision problems.<sup>6</sup>

Encephalocele		
	Number of Cases Annually	Rate per 10,000 live births
Kentucky	4	<1.0
U.S.*	341	<1.0

### Maternal Risk Factors

- Health conditions including diabetes, seizure conditions, or obesity.<sup>2</sup>
- Women who have had a previous pregnancy affected by an NTD.<sup>2</sup>
- Hispanic ethnicity, compared to Non-Hispanic Whites.<sup>7</sup>

### Prevention

Research has shown that adequate daily intake of folic acid reduces the risk of NTDs.<sup>1</sup> However, women who take folic acid may still have babies with NTDs, and women who do not take folic acid can still have healthy babies.

Early and consistent prenatal care helps a woman monitor her health during pregnancy. Her provider can promote a healthy pregnancy by helping her manage health conditions, medications, and diet.

### References

4. Centers for Disease Control and Prevention. Facts about anencephaly. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/birthdefects/anencephaly.html>. Last updated November 9, 2015. Accessed February 12, 2016.
  - 5 Brei T, Payne C, Worley G. An expectant parent's guide to Spina bifida: The answers to your questions. <http://spinabifidaassociation.org/wp-content/uploads/2015/07/EVENTANT-PARENTS-GUIDE-TO-SPINA-BIFIDA2.pdf> Spina Bifida Association. Updated July 2015. Accessed on November 19, 2015.
  6. Centers for Disease Control and Prevention. Facts about encephalocele. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/birthdefects/encephalocele.html>. Last updated October 20, 2014. Accessed February 12, 2016.
  7. Centers for Disease Control and Prevention. Key findings: Racial and ethnic differences in the occurrence of major birth defects. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/birthdefects/features/racialethnicdifferences.html>. Last updated October 21, 2015. Accessed February 12, 2016.
- \*All U.S. data from the following: Parker SE, Mai CT, Canfield MA, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. National Center on Birth Defects and Developmental Disabilities. *Birth Defects Res A Clin Mol Teratol*. 2010 Dec;88(12):1008-16. doi: 10.1002/bdra.20735.